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ABSTRACT

This executive summary describes a study to identify the concerns and needs of American Indians with disabilities living in the urban area of Denver (Colorado). The study also sought to determine if the Concerns Report Method was useful in identifying needs. The executive summary consists of a brief review of information on the urban American Indian, a review of American Indians and disability, a summary of research methods used in the study, a summary of study results, and recommendations for community change. The paper emphasizes that American Indians with disabilities assisted in designing and carrying out the research. Data from 100 interviews with American Indians with disabilities were analyzed, and the executive summary presents graphs showing the percentage of disabling conditions represented and the percentage of males and females reporting specific functional limitations. The study found that services needed include outreach, case management, affordable housing, accessible transportation, medical care, and employment opportunities. Eight recommendations are offered, along with four suggested areas of further research. The study concludes that the Concerns Report Method could be effectively used, with some modifications. (Contains 12 references.) (JDD)

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The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change: Denver, Colorado

Executive Summary

1990

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The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change

This **Executive Summary** consists of: (a) a brief review of the existing information on the urban American Indian, (b) a section on American Indians and disability, (c) a summary of research methods used in the study, (d) a summary of the results of the study, and (e) recommendations for community change. The Final Report of this study is available from the American Indian Rehabilitation Research and Training Center (AIRRTC). The Final Report describes the entire study, including process and results.

INTRODUCTION

The mission statement of the American Indian Rehabilitation Research and Training Center (AIRRTC) states "Individuals who are recipients or users of the Center's research and training efforts are included in the design, conduct, implementation, interpretation, and dissemination of Center activities" (Johnson, 1988, p. 5). In line with the AIRRTC's mission, this study identified the concerns and needs of American Indians with disabilities living in the urban area of Denver. American Indians with disabilities assisted in designing and carrying out the research. In his address titled "Self-Determination at the Community Level," Bowe (1989) recommended that service providers and researchers:

1. Help people with disabilities to acknowledge their needs openly, without shame or fear.

2. Teach people with disabilities how to influence the decision-making process in public and private organizations.

3. Guide people with disabilities in identifying allies or support groups of common cause.

The AIRRTC recognizes and supports these statements.

The Urban American Indian

During the 1950's and early 1960's, federal funds were used in an effort to draw Indian people into the majority society. A major part of this effort was relocation of American Indians to cities for jobs or job training. Upon arrival in the city, the new arrivals were usually given a check to be spent on food, clothing, and household items. Although the new arrivals were helped in finding work, many did not adjust to urban life. The work which American Indians

found was often temporary, seasonal railroad and farm work were common. Urban Indian Centers helped Indian people fill the gap created when they left their families and relatives on the reservations. The Centers gave emergency housing, food, clothing, counseling, and opportunities to meet or visit other Indian people. The Indian people shared similar needs and concerns which brought together members of various tribal groups. Relocation reached a peak between 1952 and 1957; over 17,000 persons were served (Fixico, 1986, p. 148). Today, "the end result of relocation is that over one-half of today's Indian population now resides in urban areas" (Fixico, 1986, p. 183). Many Indian people "have traded rural poverty on reservations for urban slums" (Fixico, 1986, p. 156). Metcalf (1982) stated "25 years of Relocation ... has succeeded in increasing ... the probability that young Indian families will live at least part of their lives in urban poverty and that Indian women will be raising their children in city slums" (pp. 74-75).

American Indians and Disability

AIRRTC studies have shown that rehabilitation services were provided to American Indians with disabilities at very low rates when compared to the rates of service provided to the U. S. population as a whole (O'Connell, 1987). American Indians who are disabled appear to be poorly represented in the public rehabilitation system in the areas of eye and ear disorders, orthopedic impairments due to accidents, asthma and allergies, diabetes, speech conditions, and skin conditions (O'Connell, 1987). Also, studies of state rehabilitation services used by Native Americans have shown that the rate of case closure among Native American clients was much lower than within the general population (Morgan, & O'Connell, 1987). Indian people with disabilities have problems in trying to use services in urban areas. They may not be aware of agencies which can assist them. In a survey of 38 state vocational rehabilitation administrators, cultural differences were identified as possible barriers to service (White, 1987).

METHOD

The purpose of this study was to determine the needs of American Indians with disabilities in the community through involvement of Indian people with disabilities. The Concerns Report Method was used to determine if its use would be relevant and beneficial to American Indian populations. This method was chosen because it requires the involvement of people with disabilities. Research questions were:

1. Can the Concerns Report Method be used to accurately identify the needs of American Indians who are disabled?

2. Will the information gathered by the study result in improved rehabilitation service delivery to American Indians with disabilities?

The results of Question 1 are given in the Final Report. Question 2 will be addressed in a study to be conducted in two years.

Subjects

The Denver-metro area was selected as the site for this project. Meetings were held in Denver in August, 1989, with administrators and staff of sponsoring agencies. Agencies which supported the project were: Colorado Rehabilitation Services, the Denver Indian Center, and Denver Indian Health and Family Services. Facts about the Denver community are:

1. Denver is located in Colorado, a state which ranks 19th nationally in its American Indian population. Fifty-four percent of American Indians in the U.S. live in urban areas (Bureau of the Census, 1983a).

2. In Colorado, 11.3% of Indian males and 11.6% of Indian females have disabilities. These disability rates are high when compared to those of the general U.S. population of people with disabilities (7.8% for males and 6.7% for females) (O'Connell, 1987).

3. The 1980 U.S. Census reported an American Indian population in Denver of 9,535, with 1,153 persons of age 16 and over reporting a disability (Bureau of the Census, 1983b). Other reports vary on the total American Indian population.

4. The Denver Indian community is a "multi-nation population" located mainly in Denver County. More Sioux are represented than any other tribe. There are about 50 tribes in the Denver area (John Compton, November 9, 1989, personal communication).

Sponsoring agencies were asked to help the AIRRTC in locating people to interview (people with disabilities). People who were interviewed met these four criteria:

1. American Indians with a physical, intellectual, or emotional disability,

2. American Indians 14 to 70 years of age,

3. American Indians recovering from alcoholism, if they had a second disability,

Research Process

4. American Indians living in the Denver area.

The purpose of this research was to determine if the Concerns Report Method was useful in identifying the needs of American Indians with disabilities. The survey used in this research was developed by a "working group" (Suarez de Balcazar, Bradford, & Fawcett, 1989) or research support group (AIRRTC). A meeting of service providers and Indian people from the community was held on August 29, 1989, at the Denver Indian Center. It was recommended that service providers and American Indian elders

identify members of the "working group." Members of the "working group" would include those who knew people with disabilities. It was strongly advised that the elders be invited to attend a meeting to learn of the project's purpose. Dinner was served at this meeting in line with American Indian custom. The elders were asked to bring a person to the meeting who might be interested in the "working group." On September 16, 1989, about 36 people attended the first dinner meeting at the Denver Indian Center.

Twelve of the 36 who attended were either disabled or had a family member who was disabled. They were asked to identify issues for the survey instrument. Concerns discussed were the need for the following: (a) service agencies to reach out to people with disabilities, (b) affordable and accessible housing, (c) accessible transportation, and (d) more awareness and access to information about services for American Indians with disabilities in the Denver area. It was agreed that a second meeting was necessary to finish identifying the items to be included in the survey. At the second meeting, it was suggested that items on spirituality and education be included.

The survey was conducted through face-to-face interviews. Eleven American Indians participated in a 3-day training program to prepare them as interviewers; 8 were hired as interviewers. The average age of the interviewers was 39.8 years [Range 29-60 years]; the majority [5 of 8 (62%)] were female. Four persons spoke their native language. People with disabilities were recruited through service agencies, churches, and the Indian "grapevine." Interviews were conducted (mostly in homes) from mid-January, 1990, through mid-March, 1990. Other locations for the interviews were the Denver Indian Center, Denver Indian Health and Family Services, a restaurant, a library, a hospital, and the Homeless Resource Center. The people interviewed were paid $20.00 each as a gesture of thanks.

A public meeting was held on April 17, 1990, at the Denver Indian Center. Results of the study were shared with the community of American Indians with disabilities. They were asked to give recommendations on community change. About 50 people attended the meeting. They were mainly service providers, individuals who had helped with the survey, and interviewers for the project. Some of their comments were:

- "You've got to hire Indian people to help Indian people" (Indian man).
- "So that's what the whole situation is about—social agencies, the systems that look at Indian people like, 'You're nothing; you're just a menial laborer'" (Indian man who is blind).
- "I believe that the Indian people, especially in the metro area, have been grossly underserved. I'm not going to point fingers at anyone, I think we all share responsibility to do something about it . . ." (James Weiland, State Coordinator for Native American Programs, Colorado Rehabilitation Services).

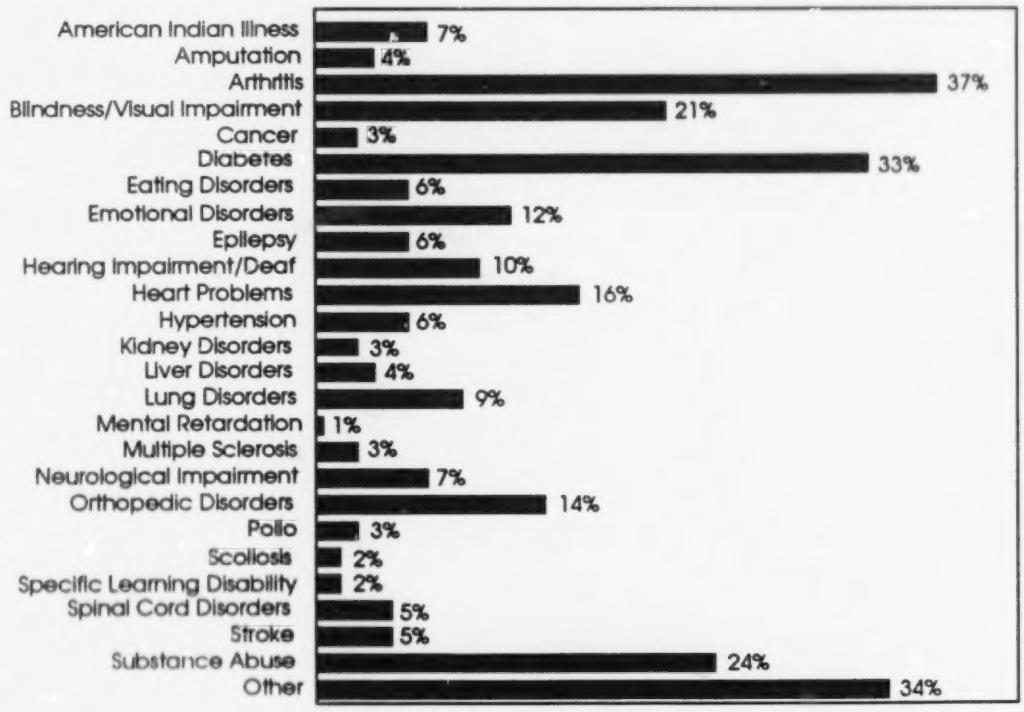
RESULTS

Data from 100 interviews were analyzed. Most of the people interviewed were Sioux (67%). Most were female (55%); the average age of those surveyed was 46.5 years. They had an average yearly income of $6,086; however the majority [56 of 97 (58%)] had incomes of less than $5,000 per year. All of them (100%) reported that they could speak English fluently; 59% reported they could speak their native language fluently. Those who were interviewed reported having lived in the Denver area an average of 18 years. One quarter (25%) of the people surveyed reported working for pay. The average yearly income of employed women was $9,667; the average yearly income of employed men was $10,800.

Disabling conditions reported by the people surveyed are listed in Figure 1. The category "Other" includes atypical vertigo, chronic pain, and AIDS, etc. In almost all activities, more females reported problems in functioning than did males (see Figure 2).

Figure 1

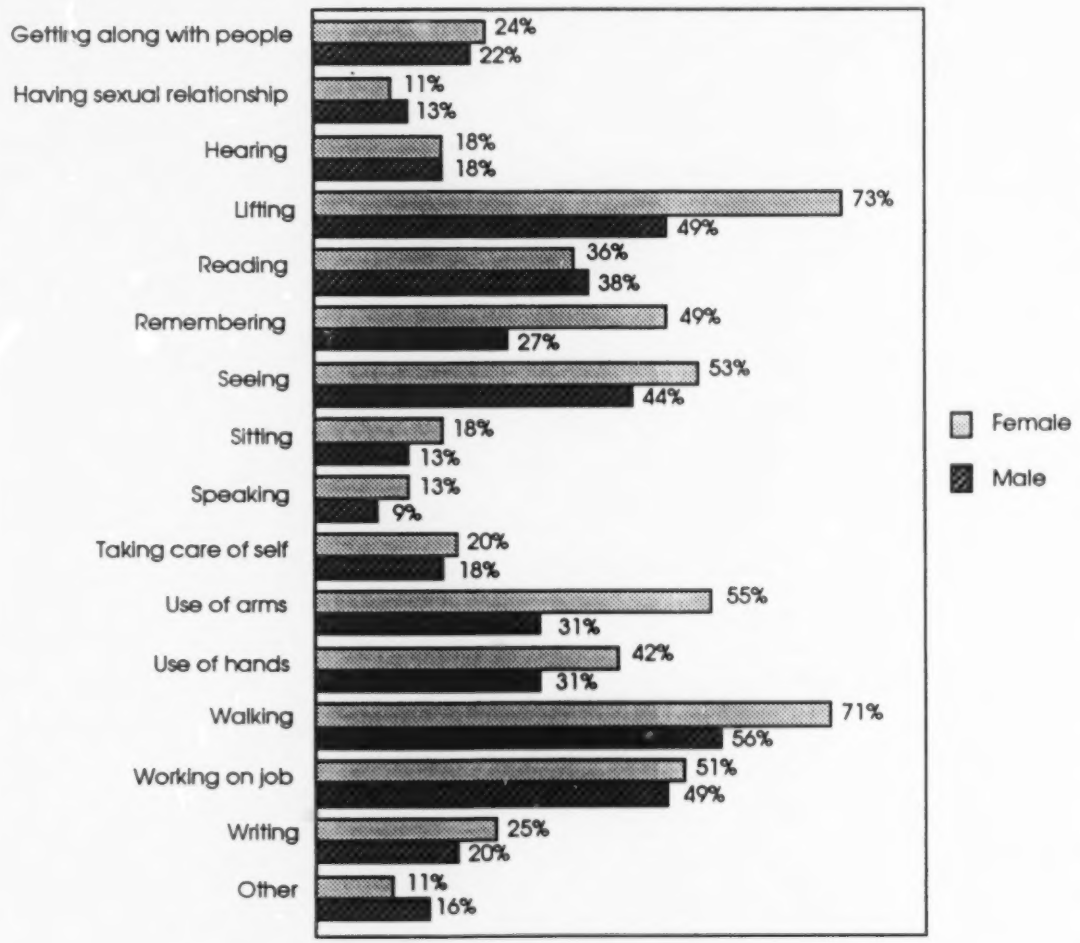
Percentage of Disabling Conditions Represented in Interviewee Population



Note. Percentages total more than 100% because many interviewees had more than one disability. American Indian Illness refers to conditions unique to American Indians.

Figure 2

Percentage of Males and Females Reporting Specific Functional Limitations



DISCUSSION

The lack of outreach from social service agencies is of great concern to the people surveyed. Case management, or the professional coordination of services to persons with disabilities, is needed. This study revealed that information about services was obtained by interviewees mainly through friends and relatives. This finding supports an earlier study which stated that family and friends of urban American Indians are important in accessing health care systems. Lewis (cited in Red Horse, Lewis, Feit, & Decker, 1978) found that Indian people who seek help begin with the family network, followed by the social network, religious leader, the tribal community, and finally the health care system.

Other concerns of the people surveyed include the lack of affordable housing, lack of accessible transportation, and lack of access to medical care; 37% reported *not* having medical insurance or assistance. The lack of employment opportunities for this population is also a concern; only 2% of those surveyed were receiving vocational rehabilitation services.

Over half of the Indian people surveyed were dissatisfied with the way they were treated by social agency workers. They were not treated with respect or dignity. There is a need for social agency workers to be sensitive to people of other cultures. Service delivery systems must be sensitive and responsive to a population, such as this one, which can function in the majority society, but is grounded in Indian culture.

CONCLUSIONS AND RECOMMENDATIONS

One research question asked in this project was, "Can the Concerns Report Method be used to accurately identify the needs of American Indians who are disabled?" The answer is "yes," with some modifications. This survey was conducted through face-to-face interviews rather than through a mail survey. Strengths of this research include involvement of the Indian community, especially in the development of the survey. The interest of the persons hired as interviewers, and the interest of the on-site coordinator, contributed greatly to the success of the project. One concern about this project is the amount of time used for the face-to-face interviews. Interviewers traveled across Denver for up to 3 hours, round-trip, during the winter months; snowstorms caused cancellations and delays. Communication problems arose from limited access to telephones; at least one interviewer, and almost a quarter (25 of 100) of the people interviewed did not have a telephone. Other problems included missed appointments for interviews, no payment to interviewers for "no show" appointments, and delays in payment to interviewers and persons interviewed.

Recommendations for change in the Denver community are based on the needs of the individuals surveyed. There are other Indian people with disabilities in Denver who may have different needs. Reid, O'Neil, Manson, Lundberg, and Joe (1990), in a panel discussion on the relationship of researchers to the Indian community, stated that community-based research requires both accountability and respect for the community. They also agreed that "it is up to the community and to the tribe to take the information from research and develop culturally appropriate programming or follow-up." In that spirit, the following recommendations are made—the community may find other directions for making change.

RECOMMENDATIONS

1. In-home outreach to identify individual needs should be conducted by those agencies wishing to serve American Indians with disabilities. This outreach should be accomplished through the use of Indian case finders, and should be coordinated by a single agency, for example, an Indian health or social services agency, in order to avoid duplication of effort.

2. Case-management services should be available to ensure that basic needs are met. Interviewees often referred to problems with transportation and access to basic health care such as dental services. They need very basic assistive devices such as glasses. Client advocates should provide case-management services through Indian service agencies.

3. Vocational rehabilitation services, which focus on the special needs of an aging workforce with multiple disabilities, should be made available within the Indian community.

4. Increased employment opportunities must be made available. While 78% of those working (25% of the survey population, or 25 individuals) reported being satisfied with their current positions, increased levels of employment must be available to those who would want them.

5. American Indians with disabilities in Denver need to organize themselves as a community. As a community, they can engage in self-advocacy activities, perhaps by increasing the number of American Indians with disabilities who are registered to vote.

6. Service agencies can help American Indians with disabilities through education and information on their legal rights, especially employer accommodation to disability and accessibility issues. These efforts will help to build their community.

7. Indian health agencies should develop education and information programs for the general Indian community which stress the "health and wellness" of disability. Information should be distributed to persons with disabilities on how to cope with their conditions and how to avoid or reduce functional limitations.

8. American Indians with disabilities want to be served by American Indians. This request and need cannot be ignored. Service agencies in Denver must renew their efforts to train, hire, and retain American Indians who serve this population.

Future research investigations. This research is only a beginning. Many more issues on the needs of American Indians with disabilities must be addressed in the Denver area, for example:

1. Efforts were made to include transition age youth (14-22 years old) in this research, however, they were not identified. Where is this age group? Are the schools taking care of their needs? Are they working?

2. Are there differences in how needs of recent arrivals in Denver are met compared with how needs are met for those who have lived in Denver all of their lives? Where do recent arrivals go first for help?

3. How easy is it for American Indians with disabilities to get health, social services and rehabilitation services?

4. The results of this study show a difference between men's and women's income, and men's and women's functional limitations. What special services, if any, should service agencies develop to address these differences?

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Contributors

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